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End-of-life decisions in the intensive care unit-exploring the knowledge and attitude of nurses and doctors: a national survey

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ABSTRACT

Aims: In Turkey, there is a growing awareness regarding end-of-life practices. It has become evident that treatments in intensive care to end-stage patients, instead of honoring their previously made end-of-life decisions, significantly diminishes patients' overall quality of life. The aim of study is drawing attention to end-of-life decision practices and to evaluate the knowledge and attitudes of intensive care physicians and nurses, who are decisive in end-of-life decision-making practices.

Methods: The study was planned as a multi-center, cross-sectional, descriptive questionnaire. There were 21 questions about demographic data, definitions, and end-of-life decisions. 259 of 760 intensive care physicians and nurses who filled out the questionnaire were included.

Results: Two hundred and fifty-nine participants were included. The rate of decision for terminal sedation and euthanasia was differentiating according to intensive care experience. Participants' knowledge was insufficient regarding withholding and withdrawal approaches. Intensive care physicians, and patients at the terminal stage of chronic disease were recommended as decision makers with the highest rate.

Conclusion: In this study, it was determined that the participants' knowledge about end-of-life decision concepts was not sufficient, and their approaches were differentiating due to experience. It is considered that there is a need for education and standardization about end-of-life decision-making process.

Keywords: End-of-life decision, terminal period, knowledge

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INTRODUCTION

Most of the deaths occur in hospitals, especially in intensive care units. It is known that 20% of deaths in the United States of America (USA) occur in intensive care units or the early period after intensive care.[1] In intensive care units (ICU), medical treatments involve using advanced life support systems, such as mechanical ventilation and dialysis, to provide organ support. These treatments utilize high technology and come with high costs.[2] In Turkey, some patients in the terminal stage of their chronic diseases are followed up in the ICU instead of applying end-of-life decisions and palliative care.[3] Integrating practices such as end-of-life decisions into the healthcare system is considered as an indicator of a country's level of development. Although our country's number of palliative care units is insufficient, it is gradually increasing.[4]

According to the American Academy of Hospice and Palliative Medicine and the American Medical Institute, palliative support is the care provided to patients with incurable, progressive diseases, considering their physical, social, religious, and existential needs. Palliative care aims to enhance the patient's quality of life.[5,6] Implementing end-of-life decisions is crucial for appropriately utilizing limited intensive care resources. With these decisions, it is known that end-stage patients experience this period more comfortably, and the period with pain is getting shorter.[3,7]

While some countries have legal regulations governing end-of-life decisions, and advanced directives, our country needs to develop and extend legislations in this regard.[8-10]

Treatments administered to trauma patients with

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irreversible severe injuries, patients in the terminal stage of chronic systemic diseases, or patients with medical conditions that cannot be effectively treated with current interventions often result in a low quality of life, futile treatments, or death. Factors such as legal regulations, cultural and religious beliefs, the opinions of patients and their relatives, as well as the approaches of the intensive care nurses and physicians who provide care, play a crucial role for applying end-of-life decisions.[8,11,12] In intensive care settings nurses and, more often, physicians are involved in this process.[13]

A literature review considering this information indicates a limited number of studies evaluating the knowledge and attitudes of nurses and physicians regarding end-of-life decisions and the individuals involved in the decision-making process. Therefore, this study aims to assess the level of knowledge among intensive care nurses and physicians regarding end-of-life decisions.

METHODS

The study was planned as a multi-center, cross-sectional, descriptive questionnaire study with the approval of Cukurova University Non-interventional Clinical Researches Ethics Committee (Date: 06.07.2018, Decision no: 79). All procedures were performed in our study by the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and ethical standards.

Between August 2018 and August 2019, 259 of 760 intensive care physicians and nurses who accepted to participate to the study and filled out the study questionnaire sent by e-mail and multimedia message were included in the study. Responses were anonymous and non-traceable to individual participants.

The questionnaire included the demographic characteristics of nurses and physicians, the duration of experience in intensive care, the unit and the institution participants work in, and definitions and questions about end-of-life decisions. End-of-life decisions are defined as follows:

Withholding Approach

The concept of not performing necessary treatments and practices. Withdrawal approach: Abandoning supportive treatment decisions.

Terminal Sedation

Treatment of pain and symptoms (even if shortening surveillance). Euthanasia: Ending the life of a well-informed patient with unbearable and insoluble pain by a doctor.

Palliative Care

Improving patients' quality of life in the end-stage of chronic disease.

End-of-life care: Supportive treatment (comfort, symptom, support) of a patient in the last period of his life.

Futile Treatment

Treatment or practices in which medical intervention is useless or ineffective, has no or little benefit to the quality of life, and does not have the possibility of responding to patient expectations.

The questionnaire form was delivered to physicians and nurses via Google Forms® over the Internet.

Statistical Analysis

The statistical analysis of the data was made with the SPSS 20.0 (Chicago IL 20.00, USA) program. Descriptive data were expressed as arithmetic mean±standard deviation and percentages. After the continuous variables were evaluated with the Kolmogorov-Smirnov test regarding whether they were normally distributed, the T-test and Mann-Whitney U tests were used for comparison. Pearson's and Spearman correlation tests were used for the correlation between variables. Chi-square and Fischer Exact tests were used to compare categorical variables. A p-value of less than 0.05 was considered statistically significant.

RESULTS

Two hundred and fifty-nine participants were included in the study. Among the participants, seventy-three (28.2%) were male, and one hundred and eighty-six (71.8%) were female. The mean age was 33.9±8.4 years.

The participants were categorized based on their professions. One hundred and nineteen (45.9%) of the participants were doctors, and one hundred and forty (54.1%) were nurses. The hospitals where the participants worked were also evaluated. Education and research hospitals accounted for 48.3%(n=125) of the participants, while university hospitals accounted for 32.8%(n=85). Additionally 12.4, %(n=32) of the participants worked in a state hospital.

The participants were evaluated based on the ICU they worked in. The percentage of participants working in the surgical ICU was 16.6%(n=43). The percentage of participants working in the medical ICU was 13.9%(n=36). Most participants, 69.5%(n=180), worked in the surgical-medical mixed ICU. The participants' experience in intensive care field is indicated in Table 1.

Table 1. Experience in intensive care

0-5 Years	50% (n=129)
5-10 Years	31% (n=80)
10-15 Years	9% (n=23)
>15 Years	10% (n=27)

After introducing the end-of-life decisions to the participants, they were asked about their familiarity with the concept, and the difference in knowledge levels between nurses and physicians was evaluated (Table 2).

Table 2. Level of knowledge of end-of-life concepts - Assessment by profession

Terms	Those who say they know the concept		Those who say they don't know the concept		p
	Nurse	Physician	Nurse	Physician	
Withholding treatment	47 (0.18%)	72 (0.28%)	93 (0.36%)	47 (0.18%)	<0.001
Withdrawing treatment	64 (0.25%)	86 (0.33%)	76 (0.29%)	33 (0.13%)	<0.001
Terminal sedation	105 (0.41%)	102 (0.39%)	17 (0.28%)	35 (0.14%)	0.03
Euthanasia	136 (0.53%)	117 (0.45%)	4 (0.02%)	2 (0.01%)	0.53
Palliative care	137 (0.53%)	116 (0.45%)	3 (0.01%)	3 (0.01%)	0.84
End of life care	122 (0.47%)	107 (0.41%)	18 (0.66%)	12 (0.05%)	0.48
Futile treatment	115 (0.44%)	105 (0.41%)	25 (0.1%)	14 (0.05%)	0.17

The study examined the relationship between the knowledge levels of physicians and nurses and their duration of working in the ICU, as shown in Table 3.

Table 3. Knowledge level of the end of life concepts-Relationship with intensive care working year

Terms	Percentage of participants knowledge about the concept (according to the duration of intensive care unit)				p
	0-5 years (n=129)	5-10 years (n=80)	10-15 years (n=23)	>15 years (n=27)	
Withholding treatment	44 (34.1%)	43 (53.8%)	10 (43.5%)	22 (81.5%)	<0.001
Withdrawing treatment	62 (48.1%)	52 (65%)	12 (52.1%)	24 (88.9%)	<0.001
Terminal sedation	95 (73.6%)	67 (83.8%)	20 (87%)	25 (92.6%)	0.06
Euthanasia	124 (96.1%)	80 (100%)	22 (95.7%)	27 (100%)	0.22
Palliative care	126 (97.7%)	78 (97.5%)	22 (95.7%)	27 (100%)	0.78
End of life care	112 (86.8%)	71 (88.8%)	20 (87%)	26 (96.3%)	0.54
Futile treatment	101 (78.2%)	73 (91.2%)	19 (82.6%)	27 (100%)	0.08

In Table 4, participants were asked about the percentage of end-of-life decisions that should be applied to the patients they had been following up in the ICU during the last month, and their responses are provided.

Considering the necessity of implementing end-of-life decisions for the patients under the care of the study participants, it was observed that the proportion of those who believed that terminal sedation and euthanasia should be applied decreased as their duration of experience in the ICU increased. There was a statistically significant difference in the responses between those who worked in the ICU for less than five years and those who worked for more than fifteen years (Table 5).

Table 4. Answers to the question "What percentage of patients you followed up in the last month should be applied to the end-of-life decision?

	Nurse Median±SD	Physician Median±SD	p	Total
Withholding treatment	27.43±68.58	21.99±22.0	0.14	24.9
Withdrawing treatment	18.94±24.51	21.60±22.5	0.04	20.16
Terminal sedation	36.5±33.97	19.53±23	<0.001	28.70
Euthanasia	12.75±22.79	7.99±16.78	0.7	10.56
Palliative care	44.26±30.76	30.60±23.10	<0.001	37.91
End of life care	40.17±31.38	28.71±25.65	0.07	34.91
Futile treatment	30.49±28.74	24.07±22.02	0.31	27.53

Table 5. Intensive care experience-Thought of necessity to implement end of life decision

	0-5 years (n=129)	5-10 years (n=80)	10-15 years (n=23)	>15 years (n=27)	p
Terminal sedation	32.88	30.14	18.96	12.81	0.006
Euthanasia	14.56	7.63	7.04	3.15	0.012

The rate of end-of-life decision-making among the participants was evaluated based on the type of ICU they worked in, whether it was a medical, surgical, or mixed ICU. It was observed that there was no statistical difference between the different types of ICUs (Table 6).

Table 6. Rate of end-of-life decision making according to the intensive care unit worked in

	Median±Standart Deviation			p
	Surgical ICU	Medical ICU	Mixed ICU	
Withholding treatment	18.02±20.56	20.41±22.73	27.48±61.31	0.67
Withdrawing treatment	17.16±20.25	25.02±24.46	19.90±24.11	0.31
Terminal sedation	27.48±27.55	32.30±28.65	28.78±31.73	0.38
Euthanasia	9.86±16.11	14.80±23.49	9.87±20.59	0.32
Palliative care	38.53±27.56	44.50±30.94	36.42±27.79	0.37
End of life care	29.07±27.15	39.75±30.63	35.33±29.59	0.28
Futile treatment	22.26±22.12	31.36±26.22	28.02±26.76	0.35

The determinants for end-of-life decisions were assessed among the participants. The rate of patients approaching to the terminal stage of their chronic disease answer was 28.6% (n=74). The rate of patients in the terminal stage of their chronic disease was 56.8% (n=147). The rate of unconscious patients' families being followed up in ICU was 47.5% (n=123). The responsible physician who followed the patient in the ICU was determined as the determinant

by 89.6% (n=232) of the participants. On the other hand, only 23.2% (n=60) of the participants suggested the nurses following the patient in the ICU as the determinant.

DISCUSSION

It is recommended to implement end-of-life decisions to ensure the appropriately utilization of intensive care beds and providing a more comfortable last period to the end-stage patients.[3] In this process, the competence and approach of healthcare professionals, who are responsible for informing and guiding patients and their families regarding end-of-life decisions, become crucial.

Our study aimed to raise awareness about end-of-life decisions and evaluate the knowledge level of physicians and nurses involved in this process. It was observed that the participants' knowledge (46%, 58%) was insufficient regarding withholding and withdrawal approaches. However, in other questions, the percentage of participants who claimed to be familiar with the concepts ranged from 88% to 98%.

In a national report conducted by Sullivan et al.[14] in 2003 in the United States, it was highlighted that only 18% of medical school students and resident physicians received education on end-of-life decision practices, indicating insufficient knowledge in this area. Consequently, curriculum development and cultural change were emphasized.[15] Several studies have evaluated the knowledge level of nurses regarding end-of-life decisions. Schrerer et al.[16] conducted a study in New York in 2013, while Patti et al.[17] conducted a study in the United States in 1998. Both studies found that nurses had insufficient knowledge about end-of-life decisions. In a multinational study by Coffey et al.[18] in 2016, nurses' knowledge level about end-of-life decisions was evaluated in different countries. The study revealed that the percentage of nurses who knew end-of-life decisions was 49% in Hong Kong, 62% in Italy, 52% in Israel, 100% in the United States, and 75% in Ireland. Comparing the studies by Patti and Coffey, published 18 years apart, it was observed that the knowledge level in the United States reached 100% due to education on end-of-life decisions. Similar to our study, other studies conducted in different countries and at different times have reported insufficient knowledge levels. However, it has been demonstrated that knowledge about end-of-life decisions can be improved through education.

When participants were asked whether end-of-life decisions should be applied to the patients they were currently following up in the intensive care unit, it was found that a high percentage of participants believed that end-of-life decisions should be implemented. This could be attributed to our country's insufficient palliative care units. As a result, patients in need of palliative care are often provided medical support in intensive care units. The high rate of patients requiring end-of-life decisions among intensive care patients may be due to the limited availability of palliative care units for terminal-stage patients who are being followed up in the intensive care unit.[19-21]

The ratio of physicians and nurses who responded to the question regarding their belief in applying end-of-life decisions was evaluated according to the ICU they worked in, no statistically significant difference was observed between the groups (surgical/medical/mixed). According to profession groups, nurses showed a higher ratio in favor of applying supportive treatment withdrawal, terminal sedation, and palliative care to patients. Nurses are involved in the self-care of terminal patients, spend more time with patients and their relatives, and have access to detailed information about the patient's previous and current functional status, as well as the treatment expectations of the patients and their families.[22] It is believed that these factors may contribute to the different responses between the two professions.

Regarding the decision-maker for applying end-of-life decisions to the patient, the participants in our study indicated that the responsible physician following the patient in the ICU had the highest ratio, followed by the nurse who cared for the patient. The patient himself or his legal guardian was also considered a decision-maker, albeit to a lesser extent. Additionally, patients approaching the terminal stage of their chronic disease were mentioned as having some involvement in the decision-making process. Similar to the findings in our study, a prospective, multi-center cohort study by Esteban et al.[13] also found that physicians were more frequently involved in the decision-making process. However, the Australian and New Zealand Intensive Care Association (ANZIC) proposal and the study by McMillen et al.[23] suggested that nurses should play an active role in end-of-life decision-making. It was argued that decisions made solely by intensive care physicians might be one-sided and potentially misleading.[24] The studies by Ahrens et al.[25] and the review by Adams et al.[26] indicated that more positive outcomes were achieved when physicians and nurses were involved in end-of-life decisions.

Study Limitations

The use of an online survey format instead of face-to-face interaction is an important limitation of this study. In addition, the number of participants below the intended target can be stated as another limitation.

CONCLUSION

As awareness surrounding end-of-life decisions continues to expand, the capacity to implement these methodologies for end-stage patients will steadily gain relevance and applicability. In this case, it is necessary to review the

competence related to this issue. Based on this, our study evaluated ICU physicians' and nurses' knowledge and attitudes who are crucial in guiding patients and their families regarding end-of-life decisions. Unfortunately, this study demonstrated that the knowledge level of the participants in this regard was not sufficient. And significant differences were observed between the attitudes of participants based on their experience in the ICU. As a result, there is a need to enhance the level of knowledge and standardize the attitudes of intensive care physicians and nurses toward the end-of-life decision process. Therefore, we propose that issues related to end-of-life decisions should be integrated into the curriculum and included in postgraduate education programs.

ETHICAL DECLARATIONS

Ethics Committee Approval: The study was carried out with the permission of Cukurova University Non-interventional Clinical Researches Ethics Committee (Date: 06.07.2018, Decision no: 79).

Informed Consent: A signed and free and informed consent form was obtained from all participants in this study.

Referee Evaluation Process: Externally peer-reviewed.

Conflict of Interest Statement: The authors have no conflicts of interest to declare.

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